An Exploration of the Interpersonal Research Experience of Participants with Schizophrenic Disorders: A Mixed Method Study

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Statement of the Research Problem

Individuals with severe and persistent mental illness, particularly those living with a schizophrenic disorder, are considered one of the most disenfranchised groups in the United States. The societal, familial and individual impact of this disease creates an ongoing, urgent need for scientific study to understand the disorder, to learn about prevention, intervention, treatment and the experience of living with schizophrenia (Roberts, 2006). Researchers worldwide are studying individuals diagnosed with schizophrenia. However, schizophrenia research often fails to address the situational interaction between a researcher and subject. Danziger (1990) reports studies regarding the social interaction between a researcher and study participant "are virtually nonexistent" (p. 10). This belief is echoed by prominent schizophrenia researchers (see Roberts, Warner, Hammond & Hoop, 2006) as well as research historians (see Orne, 1962),

Individuals with schizophrenic disorders who choose to participate in research may find themselves in a relationship with researchers. The relational phenomenon that exists and evolves between a face-to-face researcher and a research participant is the focus of this study. While the social relationship between a researcher and participant may vary from one study to the next, Danziger reported that the relationship is "always present" (1990, p.9). Thus, there is a growing need to understand how people with schizophrenia spectrum disorders understand this relationship.

The *therapeutic misconception* (TM) is one concept some researchers utilize to understand the ubiquitous presence of a relationship in research participation. The concept of a therapeutic misconception was formulated by Appelbaum, Roth & Lidz in 1982. Therapeutic misconception refers to the mistaken belief that participating in research is a form of treatment in which study participants believe therapy and research

are provided as a direct benefit to them. Numerous studies have shown that society (Dresser, 2002); clinicians (Appelbaum, Roth, Lidz, Benson & Winslade, 1987), physicians (Bamberg and Budwig, 1992) and individuals of all kinds are prone to confuse research participation with therapeutic intervention. Appelbaum, Roth & Lidz are reported to accept TM as an "inevitable consequence of conducting research with patients" (Dresser, 2002, p.290). Evidence demonstrates a high percentage of research participants with a schizophrenic disorder experience a therapeutic misconception (Lidz, Appelbaum, Grisso and Renaud, 2004). Hence, it is important to know how TM may impact the research experience among this often researched population. The expectations and understanding of face-to-face research participation, the research relationship and the significance of the therapeutic misconception on research integrity with persons living with schizophrenia are key components of this study.

Research Background and Research Questions

Studies regarding research participation are most commonly focused on issues prior to the start of a study, such as ethics (Brody, Gluck, Aragon, 2000; Dunn, Candilis & Weiss-Roberts, 2006; Shore, 2006), the informed consent process (Boothroyd & Best, 2003; Saks, Dunn & Palmer, 2006), how research with severely mentally ill populations should be conducted (Rapp, Wes & Kirsthardt, 1993), who should conduct the research and the ideology underlying research practice (Mowbray & Hotler, 2002). Limited research is available to explore the research experience from the perspective of participants with a schizophrenia spectrum disorder once the research actually begins or after it is concluded.

Although there are many similarities in techniques utilized for interviewing in the context of a research relationship and interviewing in clinical practice, there is a "paucity of literature that addresses the translation of clinical process into research methodology" (Bunin, Einzig, Judd and Staver, 1983, p.23). Additionally, Blythe, Tripodi and Briar have pointed out the distinctions between research interviewing and therapeutic interviewing are "difficult to maintain" (1994, p.105).

The purpose of this study was to explore specific exploratory research questions that are germane in understanding the research experience and the perceptions of research participants with schizophrenic disorders who participate in face-to-face research. A description of subjects' interpersonal interactions and perceptions of the research relationship can be uncovered so as to ascertain the influence various factors may have on the research experience. This study sought to explore the following main research questions:

1. What is the experience of research participants with a schizophrenic disorder who participate in face-to-face research?

2. How does the interpersonal relationship between a researcher and a participant with a schizophrenic disorder impact the research experience?
3. What role does the therapeutic misconception (Appelbaum, Roth, & Lidz, 1982) play in the experience of participating in face-to-face research for research participants who have a schizophrenic disorder?

I believe serious mental illness is a social, cultural, personal and political construct, which changes meaning over time in the mind of society, individuals, families and treatment providers, a view supported by Harvard professor of psychiatry, Dr. Arthur Kleinman (Kleinman, 1988). Any attempt to expose the experiences of an individual with mental illness must take into account the context of the individuals' experience and the social culture in which the individual is embedded. Thus, I approached this study in an effort to understand the relational and ethical components of face-to-face research through the lived experience of research participants living with schizophrenia.

Methodology

This exploratory study aimed to explore and describe the self-report of participants with a schizophrenic disorder in regard to their prior experiences in research through the use of mixed-method data gathering techniques and analysis. The specific research design used was the concurrent triangulation design. The study was guided by Harry Stack Sullivan's theory of interpersonal relationships (1953) with attention to the exploration of how therapeutic misconception may arise in the interpersonal context of research activity.

This cross sectional, retrospective study was based on participants' recollections of their most recent face-to-face research experience using a mixed-method instrument administered during a semi-structured interview. This instrument included similar items from investigations by Boothroyd (2000) and Henderson and Jorm (1990). Open-ended qualitative contingency questions were "nested" (Padgett, 1998, p. 131) to further explain the quantitative results. Questions in the instrument explored interpersonal aspects of the research interaction such as honesty, comfort level, likeability, and feelings of respect. Additional items were included to attempt to measure any presence of a therapeutic misconception. Additional areas of inquiry included the informed consent process, opinions regarding data collection procedures, participants' understanding of the purpose of research and participants' interpretations of the relationship with their former researcher. All study participants had previously participated in a face-to-face research encounter within the past 12 months. Participants were recruited based on availability by way of fliers posted at Chicago area community centers, face-to-face recruitment sessions held during morning announcements at local area group residences and distribution of fliers through a regional mental health consumer advocacy group mailing list.

Effect sizes for group differences was used to evaluate the number of participants needed for a medium effect size for each group to attain an adequate power level of .80 using .05 alpha level for the highest data analysis to be conducted. A total of 36 participants diagnosed with schizophrenia or schizoaffective disorder enrolled in this study. The majority of participants were African-American males living in Chicago, IL.

An additional consent protocol was utilized prior to the start of data collection given the emphasis on the ethics involved in research participation for vulnerable populations,. Studies show the reliability of participants' self-report is decreased when they are actively experiencing psychosis (Chesney, Larson, Brown & Bunce, 1981), hence the Evaluation to Sign Consent (Jeste, Depp and Palmer, 2006; see Appendix A) was completed with each potential subject to help determine their cognitive capacity to understand the study prior to signing the Informed Consent document.

Study data were organized into a triangulated description following the principles of mixed-method analysis espoused by Creswell and Clark (2007). A phenomenological inquiry with thematic analysis outlined by Boyatzis (1998) was utilized to learn about the meaning of the lived experiences for participants related to the experience of participating in research. This qualitative analysis technique was consistent with Sullivan's approach to knowing the meaning of our clients' life world. Member checking was completed to strengthen the reliability and validity of qualitative findings.

Due to the study's small, non-random sample, non-parametric measures of correlation such as Spearman rank correlation coefficients (r_s) were calculated for rank-order scores in the Likert Scale items. Analysis was primarily limited to descriptive statistics including cross tabulations with chi-square calculations and accompanying effect sizes to quantify the difference between groups and as a more accurate measure of the significance of any differences.

Results

Research as a personal benefit to participant

The number of participants who reported their prior research experience as a positive one exceeded 86% (N=31). One of the more compelling findings is that face-to-face research is a positive experience for individuals living with schizophrenic disorders, regardless of the methodology utilized for data collection, the gender of the researcher or the psychiatric chronicity of the subject. Most subjects who have previously engaged in a face-to-face research experience express a desire to participate again in a research study in the future. Subjects are motivated to participate in research for reasons that parallel community samples (Boothroyd & Best, 2003), including financial gain, altruism towards others living with schizophrenia, personal growth and education. However, this study's sample differs from those without a severe mental health disorder in that they were also

interested in research participation as a way to help researchers, which had not previously been identified in prior studies.

Findings support the ongoing presence of experimenter effects in the research relationship. Subjects enjoyed the attention and value awarded them as a research subject. Thus, research may be viewed by subjects as a unique opportunity for marginalized persons to be respected, valued and financially compensated for their opinions. These assumptions would support subjects' report of a positive experience of research participation

The experience of stress in research participation

Another key finding is that participants felt stress in some capacity with much greater numbers than had previously been found. The experience of stress associated with research participation was present in some form for 52.9% (N=19) of the sample, compared to 8.8% of Boothroyd's findings (2000) and 4.8% of community-based samples (Henderson & Jorm, 1990). A positive correlation was found between psychiatric chronicity and reported feelings of stress (r= .34). Subjects who reported the most stress also expressed a desire to participate in research again in the future. These findings lead me to suspect the perceived benefits of research participation outweighed the risks of harm (or stress) among these participants living with schizophrenic disorders.

The reciprocal research relationship

Non-parametric analysis of research experience variables indicates a reciprocal relationship between honesty, likeability and respect in the research relationship, as indicated in Table 1. When subjects felt their researcher was honest with them, subjects described being honest with their researcher (r_s = .573). When subjects believed the researcher liked them, subjects described liking their researcher (r_s = .440).

TABLE 1: Spearman's Rank Order Correlations Between Subjects' Feelings Towards Researcher and Subjects' Feelings Experienced From Researcher

	I respected the researcher	r^2= Percentage of shared variance
The researcher respected me	.624**	39%
	I liked the researcher	
The researcher liked me	.440**	19%
	I was honest with the researcher	
The researcher was honest with me	.573**	33%
** All correlations are statistically significant at p< .001 (two-tailed)		

It appears the former researchers and subjects had a reciprocal interaction that may have strengthened (or weakened) the interpersonal contact within the context of the

research relationship. These findings are parallel to an empirical study by Lambert and Hill (1994) regarding the impact of the therapeutic relationship on client outcomes.

Further evaluation of participants' overall research experience indicated statistically significant correlations between individual research experience variables (e.g., interest, respect, comfort and honesty) and three items exploring the potential presence of a therapeutic misconception. Subjects rated their level of agreement to the following items: (1) The researcher acted like my therapist; (2) The researcher wanted to help me; (3) The research study was supposed to help me. Results indicated a connection between subject beliefs about the personal benefit of research and their research experience. For example, subjects who reported a belief that the research was supposed to help them felt high levels of comfort with their researcher (r_s = .568) and were more likely to express agreement that their researcher was honest with them (r_s = .495). However, results showed a medium sized correlation between one of the items measuring therapeutic misconception ("The researcher acted like my therapist") and subjects' reported level of comfort with a researcher (r_s= -.478, *p*= .009). This negative correlation established that the less comfortable subjects were with their researcher, the more they reported agreement that the researcher acted like a therapist. This finding appeared to be counterintuitive to the presence of a therapeutic misconception. It appeared participants may not have been comfortable with a researcher who acted like a therapist during data collection given subjects' understanding of the role of the researcher.

Similarities and differences between a researcher and therapist

Qualitative relational findings reflected an awareness of the subjectively felt interpersonal dynamic involved in face-to-face research. Generally speaking, study participants did not interpret the research relationship as a therapeutic encounter. Subjects maintained an interpersonal distance with researchers and did not have an expectation that research would be a form of therapy. Some subjects expressed discomfort when the researcher acted in a therapeutic manner, such as offering advice or support. This findings offered triangulation of quantitative data.

A side-by-side comparison of coding categories of the similarities and differences between a researcher and therapist are included in Table 2 below. Attention is drawn to the paucity of responses under similarities (N= 35 responses) and the larger number of responses for differences (N= 60 responses) for the total sample. This is especially important data when considering many participants' responses were coded into more than one category.

TABLE 2
Comparison of Coding Categories for Similarities and Differences Between a Research and Therapist

Similarities	N*	Differences	N*
Engaged interaction	6	Interpersonal distance within relationship	10
Content of questions	5	Content of questions	13
Personal disclosure	5	Disclosure to therapist but not researcher	11
Subject is asked questions and gives answers	8	Tasks	4
Provide feedback	3	Therapist gives advice, researcher does not	8
Similar interests in mental illness	5	Purpose	7
Both express concern	1	Therapist is more concerned	1
Other responses	2	Other responses	6
TOTAL responses	**35**	**TOTAL responses**	**60**

*N= # of responses. Participants often identified more than one item that was similar or different between a researcher and a therapist. Participants may be represented in more than one category. Not all responses are included in this table.

Thus, subjects living with a schizophrenic disorder who participate in non-clinical trial research involving social, psychological or behavioral research protocols do not appear to experience a therapeutic misconception of the research process.

Utility for Social Work Practice

Social work research is needed to contribute to the development and refinement not only of practice, but also of research itself. Doing research on research is an ethical, political and social endeavor that benefits not only the social work profession, but also future research participants and methodologists. This project offers a social work presence to an understudied yet emerging body of research that is relevant to the current and future lives of this disenfranchised population.

The National Statement on Research Integrity in Social Work written by the Council on Social Work Education to "provide broad guidance and education to social work researchers" (2007) offers a starting place for understanding the ethics of research interaction. I propose the following suggestions regarding face-to-face interactions between social work researchers and study participants:

- Teach more researchers how to appropriately interact with study participants in the context of the research relationship.

- Provide special researcher-subject interaction training to encourage and teach social workers how to professionally and ethically engage in face-to-face data collection.
- Include Educational Policy and Accreditation Standard requirements in research sequence course material to specifically address researcher-subject interactions.
- Informed consent documents should explicitly identify the researcher's inability to provide therapy associated with subjects' responses to study items.
- Provide funding to support training on research projects for CSWE accredited Master's programs that require students to conduct research, for pre-doctoral candidates, doctoral students and novice researchers in the field.

These findings offer a description and exploration of the research experience from the perspective of individuals living with schizophrenic disorders that may assist in a more accurate understanding of the subjective experience of research subjects with serious mental illness. The knowledge gained from this study may be applied to future research protocols and consent procedures so that research is conducted in a sensitive manner that will not cause harm or distress to our subjects. It may also offer future social work researchers guidance on professional behaviors required in the research relationship.

The entire conceptualization of the research process should be re-evaluated to best meet the needs of participants and as a way to continue to allow research participation to be a unique opportunity for this vulnerable population to be heard and respected for their contributions. This may result in a contextual shift from researcher-driven approaches and methodologies to subject-driven approaches similar to consumer empowerment strategies and participatory action research models. Further investigation will hopefully reveal the necessary direction for research endeavors with participants living with schizophrenic disorders.

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EVALUATION TO SIGN CONSENT*

PROCEDURE:

Make a subjective judgment regarding item 1 below. Ask the patient participant 2 through 4. The researcher may select the language to use in asking the questions in order to help the participant understand them.

Participant ID _____

1. **Is the participant alert and able to communicate with the researcher?**

   *Yes*_____ *No*_____

2. **What is this study about?** *[Refers to Study Purpose section]*

   _____

   _____

3. **Can you tell me what we will be doing in this study?** *[Refers to the Procedures section]*

   _____

   _____

4. **What would you do if you didn't want to participate in the study anymore?** *[Refers to the Right to Withdraw section]*

   _____

   _____

SIGNATURE:

I hereby certify that the above person is alert, able to communicate and able to give acceptable answers to the items above.

_____

Researcher Date

*Jeste, D., Depp, C., Palmer, B. (2006). Magnitude of impairment in decisional capacity in people with schizophrenia compared to normal subjects: An overview. *Schizophrenia Bulletin, 32,* 121-128.